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Beyond Best Interests: A Question of Professional Conscience?

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1. Introduction

The litigation surrounding the future medical treatment of Charlie Gard confirmed, if there ever was any doubt, that the principle by which such cases are to be determined is the best interests of the child. Although best interests is undoubtedly the principle applied by parents and clinicians deciding together upon a child's medical treatment and by the court in disputes, I argue that Charlie's case, as with other cases in the recent body of case-law, was not a disagreement over Charlie's best interests. I argue that questions about Charlie's future medical treatment were referred to court not because continued ventilation was, in the professional opinion of the treating clinicians not in Charlie's *best* interests but, beyond that, was in their professional judgement *inimical* to his interests and, I argue, should be understood in terms of the provision of continued treatment being *contrary* to professional conscience.

In cases concerning the withholding or withdrawal of life-sustaining treatment from a child, contrary to the view of the child's parents as to what is in their child's best interests, there is a further principle, beyond best interests. Originating in the judgment of Lord Donaldson MR in *Re J*,[1] this principle is that neither the court nor parents can require clinicians to treat contrary to their professional judgement. This is cited in judgments concerned with the withdrawal or withholding of life-sustaining treatment but its meaning has not been examined in detail in the case-law, with the exception of the early judgments of Lord Donaldson MR and Hedley J in *Wyatt*.[2] The purpose of this chapter is to consider what is meant by professional judgement in this context and what effect it has in practice in terms of the circumstances in which NHS Trusts refer decisions about the future medical treatment of a child to court and the consequences

[1] *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 (*Re J*).
[2] *Re Wyatt* [2005] EWHC 2293 (*Wyatt*).

for the subsequent best interests determination. In practice decisions about the continuation of life-sustaining treatment[3] are often only referred to court where the clinicians, supported by second opinions and in accordance with professional guidance have reached the limits of what is professionally conscionable. This shift in practice, to greater accommodation of parental wishes with regard to their child's treatment, is consistent with the shift in medical law to greater respect for patient autonomy and for the responsibility of the patient for decisions about his or her treatment. Furthermore, it serves to demonstrate that not only the decision of the child's parents, in the exercise of their parental responsibility, but also that of the child's clinicians, informed by their professional conscience, is driven by caring concern for the child.

This chapter first considers the concepts of professional judgement and professional conscience. Consideration is then given to *Re J*, from which the principle that neither the court nor parents can require practitioners to treat contrary to their professional judgement originates, and the case of *Wyatt* in which Hedley J developed the concept of professional conscience. I then examine the case-law to demonstrate that although the concept may have originated as a professional judgement of the child's best interests in accordance with a competent body of professional opinion, many of the recent cases could be understood as examples of clinicians considering that not only is continued treatment not in the best interests of the child but is against the interests of the child and, as such, is contrary to their professional conscience. I demonstrate how this could be a way of understanding the case of Charlie Gard. I argue that appreciating that clinicians are seeking a ruling from the court because they have reached the limits of what they consider conscionable is important for understanding this body of case-law but more fundamentally important for parents in such cases to understand why the clinicians caring for their child can no longer treat as they wish.

2. Professional Judgement and Professional Conscience

Robin Downie and Jane Macnaughton have explained that a judgement is 'an assertion made with some evidence, or for a good reason, in a context of uncertainty'.[4] A professional judgement is one made in a professional context in which 'the uncertainty derives from the professional context and the evidence

[3] This chapter is therefore not concerned with applications to court for withholding or withdrawal of life-sustaining treatment from children in local authority care whose parents may not have the capacity to make the decision or who do not have a clear view as to their child's best interests: eg *In re Jake (A Child)* [2015] EWHC 2442.

[4] R Downie and J Macnaughton, 'In Defence of Professional Judgement' (2013) 15 *Advances in Psychiatric Treatment* 322, 322.

or relevant considerations are acquired by means of professional knowledge and skills'.[5] Professional judgement must be exercised in accordance with a competent body of professional opinion that is 'capable of withstanding logical analysis'[6] given the risks and benefits, and accord with the values of the profession as detailed in *Good Medical Practice*.[7] Diagnosis, identification of treatment options, assessment of which of the available options is clinically best, and treatment that is in the overall best interests of the child are thus professional judgements, informed by medical knowledge, experience, and critical reflection in the context of uncertainty about the efficacy of treatment and other relevant factors such as the extent to which the child experiences pain and suffering. The conclusion that there are no further treatments that can benefit the child, that continued treatment is 'futile', is a professional judgement.

In the vast majority of cases, the medical treatment of a child is provided through a partnership in which professionals, exercising their professional judgement, work together with parents, in the exercise of their parental responsibility, to identify the medical treatment that is in the best interests of the child.[8] Clinicians may, in the exercise of their professional judgement, be prepared to try a therapy even though they do not consider it to be clinically best for the child or in the best interests of the child,[9] accommodating parental wishes as far as 'professional judgement and conscience' allows.[10] Giles Birchley, in his chapter, gives examples of clinicians offering treatments perceived to be for the benefit of the parents rather than the child or delaying withdrawal of life-sustaining treatment to give parents time to come to terms with the situation.[11]

However, there are limits beyond which clinicians will not wish to go in the administration of therapies or interventions to a child which, I argue, should be understood in terms of professional conscience. As Jonathan Montgomery has observed, the 'law expects health professionals to have, and act upon, consciences'.[12] Giles Birchley has argued 'conscience has an important part to play in the delivery of health care', as he observed, we would not want practitioners to lack a conscience.[13] Although much of the academic literature is concerned with moral conscience – for example, individual moral judgements affecting the

[5] ibid.

[6] *Bolitho v City and Hackney Health Authority* [1998] AC 232.

[7] GMC, *Good Medical Practice*, www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice.

[8] *Re J* (n 1) (Lord Donaldson MR).

[9] Harm, rather than best interests, as a threshold is considered by G Birchley, 'The Harm Threshold: A View from the Clinic', chapter 6 above and D Wilkinson, 'In Defence of a Conditional Harm Threshold Test for Paediatric Decision-Making', chapter 5 above.

[10] *Wyatt* (n 2), [41].

[11] See Birchley (n 9).

[12] J Montgomery, 'Conscientious Objection: Personal and Professional Ethics in the Public Square' (2015) 23 *Medical Law Review* 200, 200.

[13] G Birchley, 'A Clear Case for Conscience in Healthcare Practice' (2012) 38 *Journal of Medical Ethics* 13, 13.

involvement of practitioners in, for example, the termination of pregnancy[14] or assisted suicide[15] – I am here concerned with professional conscience. Although moral values are an inevitable aspect of professional conscience, I am referring to a professional, and not a personal, conclusion. As Stephen Smith has argued, not all conscience claims are generalisable rules, they also arise where the provision of treatment which the professional does not have a general objection to, for example, mechanical ventilation, can no longer be provided with good conscience because, for example, it is sustaining the life of a child who has no conscious interaction and no ability to breathe independently, for whom there is no treatment and no prospect of recovery.[16] I employ Stephen Smith's three requirements for a claim to conscience, namely that the decision is based upon moral values, is owned by the individual and relates to the individual's own conduct.[17] The exercise of professional conscience involves technical expertise as well as moral choices[18] tested against professional guidance and the opinions of professional colleagues.[19] Importantly, it should be understood as a caring judgement. A conscientious decision involves individual moral choices leading the individual to act in a way that they strongly and sincerely believe is not morally wrong.[20] As Smith explains, decisions based upon conscience need not be based upon a set of rules, although they do need to be explained in general terms. As such, a view that the point has been reached that continued treatment is contrary to conscience may not have been predicted but reasons for that position must be given. Further, it is an individual decision, with which others may disagree, and as such is not 'correct' but a matter of judgement.[21] In the context of withdrawing or withholding life-sustaining treatment from a child, I argue, an individual professional judgement must be supported by the views of others, but that does not preclude disagreement. Practitioners, Giles Birchley has argued, should be encouraged to listen to their consciences although they must also be prepared for them to be subjected to challenge.[22]

[14] Abortion Act 1967, s 4 provides for conscientious objection to participation in treatment. Considered by S Fovargue and M Neal, 'In Good Conscience: Conscience-Based Exemptions and Proper Medical Treatment' (2015) 23 *Medical Law Review* 221; S McGuinness and M Thomson, 'Medicine and Abortion Law: Complicating the Reforming Profession' (2015) 23 *Medical Law Review* 177; Montgomery (n 12).

[15] R Huxtable and A Mullock, 'Voices of Discontent? Conscience, Compromise and Assisted Dying' (2015) 23 *Medical Law Review* 242.

[16] *Re A (A Child)* [2016] EWCA Civ 759.

[17] S Smith, 'Individualised Claims of Conscience, Clinical Judgement and Best Interests' (2018) 26 *Health Care Analysis* 81, 84.

[18] Montgomery (n 12).

[19] Dominic Wilkinson has argued that clinicians should provide treatment that is legally and professionally accepted despite a personal belief that this is morally wrong: D Wilkinson, 'Conscientious Non-Objection in Intensive Care' (2017) 26 *Cambridge Quarterly of Healthcare Ethics* 132.

[20] S Smith, 'A Bridge too Far: Individualised Claims of Conscience' (2015) 23 *Medical Law Review* 283, 286–87.

[21] Smith (n 17), 84.

[22] Birchley (n 13).

3. Professional Conscience in Children's Medical Treatment

In reaching his judgment following the hearing in April 2017 Francis J applied the established framework for judicial determination of the best interests of the child to the evidence presented on behalf of Charlie's parents, Guardian and GOSH.[23] Francis J did not cite the principle which originated in the obiter comments of Lord Donaldson MR in *Re J (1990)*,[24] that neither the court, nor parents, can require clinicians to treat contrary to their professional[25] judgement.[26] Lord Donaldson continued to say that parents cannot insist on treatment, and doctors can refuse to administer treatment which they consider to be 'medically contra-indicated or for some other reason is a treatment which they could not *conscientiously administer* [emphasis added]'.[27] As demonstrated below, given the more recent cases, it would be more accurate to use the terminology employed by Hedley J in *Wyatt* that clinicians cannot be required to treat contrary to their professional conscience.

Charlotte Wyatt had a range of medical problems, as a result of her premature birth at 26 weeks gestation, including chronic respiratory and kidney problems and profound brain damage. A year after the Trust had successfully applied for a declaration that ventilation would not be in Charlotte's best interests if she suffered a respiratory arrest and given improvement in her condition, Charlotte's parents applied for a discharge of the declaration whilst the Trust made a 'novel' application for authority, in the event of an irreconcilable disagreement about her treatment, for decisions to be made by her doctors.[28] The relationship between her parents and the hospital had become volatile and acrimonious; her parents had made complaints to the police about Charlotte's care and were only permitted to visit her accompanied by security.[29] Hedley J discharged the declaration which had the effect of returning responsibility to consent to the provision or withholding of ventilation to Charlotte's parents. In these circumstances, Hedley J was concerned to explain clearly the nature and limits of the legal and professional duties doctors owe to their child patient. Hedley J stressed that where the patient

[23] *GOSH v Yates & Gard* [2017] EWHC 972, [35]–[43].

[24] *Re J* (n 1).

[25] *King's College Hospital NHS Foundation Trust v MH* [2015] EWHC 1920 (*King's College Hospital*), [34] 'It is important to note that the court has no power to *require* doctors to carry out a medical procedure against their own professional judgement'; *GOSH v NO & KK & MK* [2017] EWHC 241, [23] quoting *MH* rather than *Re J* (n 1); *A Local Authority and An NHS Trust v MC & FC & C* [2017] EWHC 370, [42]; *King's College NHS Trust v Thomas & Haastrup* [2018] EWHC 127, [1]; *An NHS Trust v A & B & C* [2018] EWHC 2750, [30] quoting *MH* rather than *Re J*.

[26] Baker J expressed the principle as 'Importantly, therefore, the courts cannot compel a doctor to act in a way that he considers to be contrary to the patient, although it may of course be the case that another doctor would take a different view.' *An Hospital Trust v GM, DK, HK* [2017] EWHC 1710, [22].

[27] *Re J* (n 1), 41 (Lord Donaldson MR), repeated as part of his ratio in *Re J (A Minor) (Child in Care: Medical Treatment)* [1992] 3 WLR 507 (*Re J No2*), 516.

[28] *Wyatt* (n 2), [14].

[29] ibid, [17]–[26].

lacks competence the doctor's duty is to act in the patient's best interests and to work in partnership with the child's parents,[30] accommodating parental wishes where to do so is not an 'affront to the clinician's conscience'.[31] Hedley J delineated four categories in which disagreement may arise between parents and clinicians about a child's medical treatment:

(i) Where a doctor advocated treatment which parents resisted (eg a blood transfusion) and a failure to administer such treatment would be an affront to that doctor's conscience;
(ii) Where a doctor advocated treatment which the parents resisted on grounds that, whilst reasonable, were contrary to the clinician's view;
(iii) Where parents wanted treatment, which the clinician could not advise, but the giving of which would not be an affront to conscience; and
(iv) Where the treatment requested would be an affront to conscience.[32]

The judge observed that the majority of disagreements fall into the middle two categories and that all the clinicians giving evidence to the court agreed that 'in those circumstances they would, in the last resort, accommodate the views of the parents; and that is as it should be'.[33] But Hedley J continued, quoting *Re J (1992)*, to state that professionals cannot be required to act contrary to their professional conscience.[34] Acting according to professional conscience was, Hedley J explained, an 'intellectual' process in which the doctor must take account of all the circumstances, professional guidance and second opinions, to conclude what is in the patient's best interests and consider whether there is a 'reasonable basis' for the provision of the treatment even if he is inclined against it.[35] The judge explained that professional conscience is more of an intuitive than rational confirmation of the intellectual conclusion and 'honed by experience of patients, exposure to the practice of colleagues, and the ethos of his work'.[36] Hedley J tentatively concluded that:

> [W]here a clinician concludes that a requested treatment is inimical to the best interests of the patient, and that his professional conscience, intuition or hunch, confirms that view he may refuse to act and cannot be compelled to do so, though he should not prevent another from so acting, should that clinician feel able so to do.[37]

Hedley J was not referring to the legal duty to act in accordance with a competent body of professional opinion, or the professional duty to act in the best interests of the child as in the majority of cases where treatment decisions are reached by doctors and parents working in partnership. He was referring to circumstances in which the professional judgement is not only that the treatment is not in the best interests of the patient but that it is 'inimical' to the best interests of the patient

[30] ibid, [29].
[31] ibid, [30].
[32] Ibid, [30].
[33] ibid, [31].
[34] ibid, [32].
[35] ibid, [34].
[36] ibid, [35].
[37] ibid, [36].

and further contrary to professional conscience. Although Hedley J used the term 'professional conscience', it is clear from his exposition of the concept that he was referring to the discharge of professional duties rather than a process of examining individual or personal conscience. As Sara Forvargue and Mary Neal have argued, Hedley J was not here referring to a 'general right of conscience'.[38] It is clear from his exposition that Hedley J was contemplating *individual professional* judgements[39] rather than *personal* judgements upon the medical treatment of a child. The judge was not considering 'predictable' 'generalisable rules' such as a conscientious objection to the termination of pregnancy but 'practices which the doctor does not usually object to but does so in *this* instance on *these* facts'.[40] What Hedley J seemed to be contemplating in *Re Wyatt* was a professional judgement of the limits of what is acceptable in the provision of treatment or medical intervention given the current diagnosis and prognosis, second opinions and professional guidance. Hedley J was, I argue, invoking a concept of 'conscientious professional discretion'.[41] As such it might be what Stephen Smith has argued is 'a 'bridge too far', so that treatment previously provided has now become 'objectionable',[42] or the child's condition deteriorated so that what may have once been in the child's best interests or whilst not the best option within the range of acceptable options or something that it is acceptable to do at parental request has crossed a line and become unconscionable. Inevitably, it is also the case that the provision of treatment or continued treatment is not in the child's best interests. Clinicians may also use terms such as futile or unethical.[43] But, I argue, the benefit of understanding the decision in terms of professional conscience it to understand that a professional judgement has been reached, supported by independent opinion, that to be asked to continue to treat is to be asked to do something they consider to be professionally wrong. I now turn to consider the case-law, which I argue demonstrates a shift from professional judgement about a child's best interests to the limits of what is professionally conscionable.

4. Ending Life-Sustaining Medical Treatment: From Professional Judgement to Professional Conscience?

In *Re J (1990)* there was 'no real difference of opinion' between J's parents and clinicians but the decision as to J's future medical treatment was a matter for the

[38] Fovargue and Neal (n 14), 225; such as statutory provisions providing for conscience-based exemptions to provide specific services such as those in relation to abortion or assisted reproduction, Abortion Act 1967, s 4; Human Fertilisation and Embryology Act 1990, s 38.

[39] Smith (n 17), 83.

[40] Smith (n 20), 284.

[41] Montgomery (n 12), 201.

[42] Smith (n 20), 284.

[43] Futility was defined by Francis J in *GOSH v Yates & Gard* [2017] EWHC 972 as of 'no effect but may well cause pain, suffering and distress' [49] and as 'pointless or of no effective benefit' [93]; *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 308, [51].

court as J was, for unrelated reasons, a ward of court.[44] The question was whether it was in J's best interests to be ventilated in the event of a crisis where this would enable him to survive a life-threatening event but further compromise his quality of life. The application of the principle that neither parent nor the court can require clinicians to treat contrary to their professional judgement had the consequence that the professional judgement of the child's best interests prevailed.[45] In *Re C*, as the unanimous evidence of the doctors was that reventilation was not in C's best interests, the court could not make an order which would require the clinicians to 'undertake a course of treatment which they are unwilling to do'.[46] Cazalet J in *A National Health Service Trust v D* stated that the court could not require clinicians to treat contrary to their clinical judgement of the best interests of the child but emphasised that clinicians were at liberty to reassess *D* upon admission and provide ventilation if appropriate.[47] Counsel for the Trust, parents and Official Solicitor in *Royal Wolverhampton Hospital NHS Trust v B* were agreed that the court cannot order treatment overriding the clinical judgement of the child's doctors.[48]

This too was the application of the principle in respect of the future treatment of Charlotte Wyatt. In the first application to court in October 2004 when Charlotte was one year old, the view of her clinicians was that she would suffer a fatal respiratory infection over the winter. Although it was agreed that she should be maintained in her present condition, medical opinion was unanimous that in the event of respiratory infection it was not in her best interests to ventilate her. Hedley J considered the dispute to fall into the third category of cases he identified (above), in that all medical experts were agreed that it was not in Charlotte's best interests to reventilate but that an elective tracheostomy or initial ventilation was not an affront to their professional conscience.[49] Making the declaration, Hedley J emphasised that it was permissive and, consequently, it would be lawful to withhold ventilation but the clinicians should act according to their clinical judgement of Charlotte's best interests.

A year later, Hedley J summed up the evidence before the court which was that, apart from Dr G, all were agreed that Charlotte should be provided with all treatment other than invasive intensive care. If she survived mechanical ventilation it would in all likelihood cause a significant deterioration in her condition from which she was unlikely to recover but it was doubtful whether she would

[44] *Re J* (n 1).

[45] In *An NHS Trust v MB* [2006] EWHC 507, Bodey J stated his conclusion that continued ventilation was in MB's best interests in the widest sense but that applying the principle that a judge has no 'right or power' 'to require doctors to carry out a positive medical intervention against their own judgment' [54], he did not make a declaration to that effect, [90].

[46] *Re C (a minor) (medical treatment)* [1998] 1 FLR 384.

[47] *A National Health Service Trust v D* [2000] 2 FLR 677.

[48] *Royal Wolverhampton Hospital NHS Trust v B* [2000] 2 FCR 76.

[49] *Portsmouth NHS Trust v Wyatt & Wyatt, Southampton NHS Trust Intervening* [2004] EWHC 2247, [18].

survive and so ventilation would deny her a 'peaceful death'.[50] Concluding that it was not in Charlotte's best interests to die while receiving futile, aggressive, treatment, Hedley J noted:

> Dr H and Dr A came close to saying that such treatment would be inconsistent with professional conscience. Others, like Dr F and Dr I, did not go that far but expressed firm views that such treatment would not accord with her best interests.[51]

However, a careful reading of the more recent cases demonstrates a greater willingness on the part of clinicians to continue to treat at the request of parents only seeking a declaration of the court where continued treatment is, in professional judgement, not only not in the best interests of the child but, in the professional judgement of clinicians antithetical to the interests of the child[52] and, as such, could be considered to be contrary to professional conscience in the sense detailed by Hedley J in *Wyatt*. As such, they have reached the limits of what is possible and permissible. For example, *An NHS Trust v W and X* concerned 11-year-old X who had, three months earlier, contracted a virus that compromised his heart functioning. He was admitted to hospital with end-stage heart failure and was fitted with devices as a temporary measure prior to a heart transplant, for which there were long waiting lists. X's lung functioning was deteriorating, caused in part by a blood clot around his left lung, his chest had to be kept open (increasing

[50] *Wyatt v Portsmouth NHS Trust and Wyatt (By her Guardian) (No 3)* [2005] EWHC 693, [15].

[51] ibid, [16].

[52] *Royal Wolverhampton Hospital NHS Trust v B* [2000] 2 FCR 76, chronic lung disease which was 'necessarily non-reversible, and that to offer her intensive support would only delay the inevitable'; *Re L (Medical Treatment: Benefit)* [2004] EWHC 2713, incurable genetic condition, any treatment merely palliative; *Re OT* [2009] EWHC 633, [71], mitochondrial condition, 'Future treatment is futile and will only escalate his suffering'; *Re RB* [2010] 1 FLR 946, inherited muscular disorder caused by genetic defect, congenital myasthenic syndrome, 'the prospect of effective treatment … which would involve both identifying the defective gene and relying upon the development of a new pharmaceutical, must be many years down the line' [5]; *NHS Trust v Baby X and others* [2012] EWHC 2188, cardiac arrest resulting in catastrophic brain damage rendering him profoundly unconscious with no spontaneous purposeful movement so that there was 'no chance of recovery and no purpose in treatment' [20]; *An NHS Foundation Trust v AB and CD and EF* [2014] EWHC 1031, untreatable incurable neurodevelopmental disorder; *King's College Hospital NHS Foundation Trust v T, V, and ZT* [2014] EWHC 3315, the judge referred to the 'unanimous opinion of the five treating consultants that continued treatment serves no purpose and confers no benefit on the baby' who had irreversible brain damage [23]. A second opinion from a consultant neonatologist, in December 2013, expressed the opinion that 'the baby had suffered catastrophic brain damage, which rendered him unable to move or to breathe for himself without hope of survival without invasive ventilation' [8]. Ten months later, when Russell J made declarations that it was lawful to withdraw ventilation, there had been no improvement only deterioration and there was no prospect of improvement; *Central Manchester University Hospitals NHS Foundation Trust v A and others* [2015] EWHC 2828, children were 'artificially surviving', their condition was irreversible and could only deteriorate further [25] such that 'prolongation of the treatment not only futile but unjustifiable' [18]; *An Hospital Trust v GM, DK, HK* [2017] EWHC 1710, nothing to be gained from further neurosurgical intervention, no prospect of any recovery, condition will continue to deteriorate and baby will not survive long [21]. The unanimous medical evidence before the court in the case of Isaiah Haastrup was that ventilation would sustain his life but there was no therapy or treatment available and, due to the severity of his brain damage, there no prospect of recovery or improvement, *King's College NHS Trust v Thomas & Haastrup* [2018] EWHC 127.

the risk of infection), his kidney function was deteriorating, his muscles were wasting, his skin was breaking down. He had to be given the maximum dosage of ketamine to make any procedure, such as turning, tolerable. Due to these complications, X was no longer suitable for a transplant. The Trust sought a declaration that it was not unlawful to withdraw the devices which were keeping him alive. His surgeon's evidence was that they had

> left no stone unturned in their attempts to treat this young boy and have nothing left to offer that can achieve a promising future. In my opinion, we are lengthening X's suffering without any chance of success; this is as futile as it can get.[53]

Bodey J concluded that the 'evidence points all one way';[54] that 'the limits of what is technically feasible' had been reached,[55] X was in extreme pain and the devices were merely prolonging an inevitable death.

In *An NHS Trust v A & B & C*, having unsuccessfully tried eight medications in an attempt to control C's seizures which daily required bagging and regularly required cardiopulmonary resuscitation (CPR), graphically described in the judgment, the clinicians responsible for his care, supported by second opinions, had reached the conclusion that there was no treatment available which could restore his health or improve his condition. The medical evidence was that the continued use of bagging and CPR after the trial of the 'final option' medication had proved unsuccessful was merely delaying an inevitable death. Russell J noted, 'There can be little doubt that the discomfort felt by the medical professionals reflects their reluctance to continually inflict pain and distress to C.'[56] To do so when there was no treatment they could offer to improve his condition and when death was inevitable was contrary to his interests and, it could be argued, the professional conscience of those responsible for his medical care.

In *GOSH v NO & KK & MK*,[57] Great Ormond Street Hospital sought a declaration of the court that it would not be in the best interests of eight-month-old MK, who had been diagnosed prior to birth with a heart condition which carried a high risk of mortality, to have further aggressive treatment but that care should be reoriented to palliative care. MK had undergone heart surgery, but due to complications it had not been possible to perform the necessary second-stage operation. At a meeting of her treating team it had been agreed that there were no further surgical options available, a view shared by clinicians at Evelina and Birmingham Children's Hospital. Russell J noted that: 'All the medical opinion is that MK is not in a clinical position to receive any further surgical treatment.'[58] There was no medical or nursing evidence or opinion before the court supporting the continuation of active treatment. For the Trust it was argued that to administer

[53] *An NHS Trust v W and X* [2015] EWHC 2778, [16].
[54] ibid, [26].
[55] ibid, [17].
[56] *An NHS Trust v A & B & C* [2018] EWHC 2750, [44].
[57] *GOSH v NO & KK & MK* [2017] EWHC 241.
[58] ibid, [8].

'further painful and invasive medical interventions in circumstances where her death is both imminent and inevitable will confer on her no medical benefit, cause her unnecessary pain, suffering and distress and would not be in her best interests'.[59] The judge concluded that MK was 'dying and nothing can be done to reverse that process' and that the ventilation and CPR her parents wanted her to have would cause her suffering but only 'delay her death by a very short time'.[60] Although the case appears to be one of a disagreement about the best interests of a child for whom there was no active treatment, for her clinicians to put her to the risk of anaesthesia and consequent sedation for ventilation or to carry out CPR on a child who had had two heart operations could be seen as not only not in her best interests but inimical to her best interests and unconscionable. The evidence before MacDonald J in *King's College Hospital NHS Foundation Trust v MH* was that to intubate and provide artificial ventilation to seven-year-old Y who had spinal muscular atrophy type 1 and showed no evidence of cognitive activity following cardiorespiratory arrest would not 'alter her prognosis' but would lead to 'an unquantifiable period of time having her life artificially maintained on an intensive care unit' from which she would never leave.[61]

With evident distress, in his evidence the treating clinician in *Re A* told the court:

> This is the first time in my twenty-seven years I'm coming here and it is prolonging a suffering and we are here. It was not an easy decision for the whole team to come here. I mean, we thought long and hard. It is not only the 8 paediatric intensive consultants, it is 80–100 odd nurses, it is the neurology team, the neurosurgery team, it is the physiotherapists. Everything together, we decided that it is not in A's best interest to continue this type of intensive care to keep him alive. He is not benefiting from any of this and that is why we're here, so that deferring it, and for us, we think that it is inhuman to keep A-a suffering like that. That's why we're here.[62]

This position was articulated on behalf of the Trust in *An NHS Trust v AB*:

> Miss Powell explained to the court that the medical team have now reached the stage where they would decline to treat AB as it would be unethical so to do. When asked by my Lord, McCombe LJ, whether that was the same as a best interest test, she said that it was not. What it represented, she told the court, was that we have now reached a state of affairs where the clinicians have come to the view that AB's clinical condition is such that life preserving treatment is so contrary to her best interest that it would be inimical to their respective Hippocratic oaths to treat her and would therefore be unethical.[63]

[59] ibid, [15].

[60] ibid, [43].

[61] *King's College Hospital* (n 25), [22], urgent out-of-hours telephone hearing. Final orders were made the following week by which time the father was no longer opposed to the application but did not want to make the decision, *King's College Hospital NHS Foundation Trust v Y & MH* [2015] EWHC 1966.

[62] *Re A (A Child)* [2016] EWCA Civ 759, [17], ventilation was keeping alive A who had catastrophic injuries following an accident which meant he could not feel anything below his neck, did not respond to noise, had no sign of awareness of his surroundings, was minimally conscious and had no spontaneous respiratory effort [6].

[63] *An NHS Trust v AB* [2016] EWCA Civ 899, [23].

In the case of Alfie Evans,[64] Hayden J considered at length the medical evidence of those responsible for his care at Alder Hey, the second opinions secured by the Trust and from the parents' expert, and the views of clinicians from Rome and Munich who were prepared to accept him as a patient. Although he had at that time no diagnosis, his clinicians were of the opinion that there were 'no more tests which can now sensibly be undertaken',[65] and there was no medical treatment available to him. The medical evidence was that his brain had been irrecoverably devastated by a progressive, ultimately fatal neurodegenerative condition such that continued ventilation sustained his life but there was no prospect of any recovery of his brain function. As judgements about professional conscience are individual judgements, although ones that needs to be supported by other professionals, where it is not contrary to the conscience of another professional to treat a transfer should be arranged if it is safe to do so.[66] The clinicians in Rome and Munich did not have a different opinion about Alfie's prognosis or treatment options but rather upon the management of his end-of-life care. The hospital in Rome was prepared to offer long-term ventilation and feeding by nasogastric tube, the German doctor to provide home ventilation and training for his parents in its use. As Hayden J observed this distinction was a matter of personal belief not professional judgement.[67] Further, his clinician considered that transfer risked sudden and undignified death and where that was proposed for 'treatment' which would be of no benefit, '[a]s treating doctors we cannot in *good conscience* agree that by simply transferring Alfie to another hospital (to continue prolonged treatment which is of no benefit to Alfie) that we are acting first and foremost in Alfie's best interests [emphasis added]'.[68]

5. Professional Conscience in the Care of Charlie Gard

Charlie's life had been sustained by mechanical ventilation while the doctors at Great Ormond Street Hospital explored all therapeutic options, including nucleoside bypass therapy. Initially prepared to try nucleoside bypass therapy, as it had not been tested or used in patients with Charlie's condition,[69] they prepared an application to their Clinical Ethics Committee. Before this application could be made, Charlie suffered seizures that his treating doctors considered caused him irreversible brain damage. In these changed circumstances, his clinicians in the

[64] *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 308.
[65] ibid, [59]. His condition GABA-transaminase deficiency was diagnosed post-mortem.
[66] *Re J No2* (n 27), 518.
[67] *Alder Hey Children's NHS Foundation Trust v Evans* [2018] EWHC 308, [44].
[68] *In the Matter of E* [2018] EWCA Civ 550, [22].
[69] For an analysis of the role of the courts in cases of experimental treatment, see S Fovargue, 'Preserving the Therapeutic Alliance: Court Intervention and Experimental Treatment Requests', chapter 8 below.

exercise of their professional judgement believed that it was no longer in Charlie's best interests to try the therapy. His clinicians considered that trial of the therapy was futile and consequently, as it was agreed that his 'present quality of life is one that is not worth sustaining',[70] it was in his best interests for ventilation to be withdrawn. Charlie's parents disagreed. In the exercise of their parental responsibility, Charlie's parents reached a considered decision that continued ventilation to enable a trial of nucleoside bypass therapy was in Charlie's best interests and that the therapy offered a chance which Charlie should be given. Charlie's parents thus disagreed with his clinicians' judgements about best interests, futility and the ethics of trial of the therapy.

Charlie's clinicians reached a conclusion about his best interests after considering all the circumstances, that is, his diagnosis and prognosis, and their professional judgement that the therapy would be of no benefit. In multidisciplinary meetings they reviewed the evidence from the US doctor. They secured second opinions from St Mary's, Southampton, Newcastle upon Tyne NHS Foundation Trust and the independent expert for the parents from Southampton General to test whether there was a reasonable basis for trial of the therapy informed by the practice of colleagues. Withdrawal of ventilation was in accordance with the Royal College of Paediatrics and Child Health good-practice framework.[71] On the basis of this evidence, trial of the therapy and consequently continued ventilation for that purpose was not in Charlie's best interests, nor was it within the range of acceptable options, or an option to which they could accede to at parental request. Given that their professional judgement was that Charlie had no spontaneous respiration, no purposeful response, was not capable of spontaneous movement, his condition was deteriorating, irreversible and the invasive procedures necessary to sustain his life were probably causing him pain and suffering,[72] to continue with those life-sustaining procedures could be seen to be antithetical to his interests.

Considering whether to grant a further stay of the declaration to enable the European Court of Human Rights to consider the parents' application, Lady Hale observed that it was lawful for the clinicians to continue to provide ventilation and artificial nutrition and hydration. However, following the conclusion of Francis J that it was not in Charlie's best interests, his clinicians felt that it was 'professionally wrong' to continue to act 'otherwise' and 'contrary' to his best interests.[73] Although this was in the context of the determination by Francis J of Charlie's best interests, the judge had confirmed their professional judgement of Charlie's best interests. I argue that they had reached the point where they could

[70] *GOSH v Yates & Gard* [2017] EWHC 972, [48].

[71] RCPCH framework for good medical practice, V Larcher, F Craig, K Bhogal, D Wilkinson and J Brierley, 'Making Decisions to Limit Treatment in Life-limiting and Life-threatening Conditions in Children: a Framework for Practice' (2015) 100 *Archives of Disease in Childhood* 1.

[72] *GOSH v Yates & Gard* [2017] EWHC 972, [58], [88], [114].

[73] *In the matter of Charlie Gard (Permission to Appeal Hearing)*, 19 June 2017, www.supremecourt.uk/news/latest-judgment-in-the-matter-of-charlie-gard.html, [15] [17].

no longer, in all good conscience, participate in the provision of ventilation to maintain his life at the point at which, unable to persuade his parents, the Trust applied to court for the court to exercise its inherent jurisdiction. I argue that Charlie's case could and should be understood as only being referred to court when his clinicians believed that continued ventilation for the provision of a therapy that in their professional judgement was futile was not only not in Charlie's best interests but, furthermore, was 'professionally wrong'[74] was 'otherwise', perhaps 'inimical', to his best interests. To do so would be causing harm to a child in their care, which was contrary to their conscience.

6. Why is Consideration of Professional Conscience Significant in Children's Medical Treatment Cases?

Best interests, long-established and recently confirmed by the Supreme Court in Charlie's case as the principle by which judges determine disputes between professionals and parents as to whether it is lawful to continue to treat a child, has proven resistant to challenge. However, it has not been the purpose of this chapter to do so.

The purpose of this chapter has been to identify a shift in the circumstances in which cases are being brought to court for authority to withhold or withdraw life-sustaining treatment from a child.[75] Analysis of the early case-law demonstrates that court authority was sought when clinicians wanted to treat in accordance with their professional judgement as to a child's best interests. Now, the majority of cases are brought to court only when the responsible clinicians have reached the conclusion that to provide the treatment the parents have requested is contrary to the interests of the child and continued treatment is contrary to their professional conscience. If, as the wealth of academic literature reflecting upon changes in the doctor–adult patient relationship and its legal regulation argues,[76] patients

[74] *In the matter of Charlie Gard (Permission to Appeal Hearing)*, 8 June 2017, www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html, [15].

[75] J Brierley, J Linthicum and A Petros, 'Should Religious Beliefs Be Allowed to Stonewall a Secular Approach to Withdrawing and Withholding Treatment in Children?' (2013) 39 *Journal of Medical Ethics* 573, identify steps taken to resolve disagreements including discussions with the multidisciplinary team, assistance of religious leaders, ethical reviews, second opinions and the Patient Advice and Liaison Service.

[76] With *Montgomery* being understood by many commentators as a continuation of the trajectory in which the law has been travelling towards recognition of patient autonomy: R Heywood and J Miola, 'The Changing Face of Pre-operative Medical Disclosure: Placing the Patient at the Heart of the Matter' (2017) *LQR* 296; JM Laing, 'Delivering Informed Consent Post-Montgomery: Implications for Medical Practice and Professionalism' (2017) 2 *Tottel's Journal of Professional Negligence* 128. Although Jonathan Montgomery and Elsa Montgomery argued that the principle of respect for patient autonomy was only upheld by failing to respect the choices and characteristics of the patient: J Montgomery and E Montgomery, 'Montgomery on Informed Consent: An Inexpert Decision' (2016) 42 *Journal of Medical Ethics* 89.

are regarded not as passive recipients of care but as autonomous decision-makers, rights-holders and increasingly 'consumers exercising choices',[77] in the context of the medical treatment of children, it is parents who are claiming rights and making choices. Parents, like the patients recognised in *Montgomery*, are able to secure information about symptoms, investigations, treatment options, risks and side-effects via the Internet and from patient support groups and other sources of information. Like adult patients, parents are 'capable of understanding that medical treatment is uncertain of success and may involve risks, accepting responsibility for the taking of risks affecting their [children's] lives, and living with the consequences of their choices'.[78] But choices can only be made from the options available, which may include those that clinicians consider not to be in the best interests of the child but those they are prepared to provide. But a change in circumstances can mean that what was once an acceptable option has become an affront to professional conscience.

The best interests of the child is a titanic principle that is inured to erosion in either courtroom or practice. Stephen Smith has argued that where claims to conscience are at issue the reasons the doctor cannot provide the requested treatment become wrapped up within the best interests assessment,[79] as they did in Charlie's case. The Court of Appeal in *Wyatt*, and the appeal courts in *Gard* rejecting the arguments for a threshold of significant harm, emphasised that when the matter has been referred to court

> the forensic debate should, in our judgment, be unfettered by any potentially contentious glosses on the best interests test which are likely either inappropriately to shift the focus of the debate, or to restrict the broad exercise of the judicial discretion involved in balancing the multifarious factors in the case.[80]

In practice, however, the move seems to be to the position set out by Hedley J in *Re Wyatt*, that the clinician

> does not take orders from the family any more than he gives them. He acts in what he sees as the best interests of the child: no more and no less. In so doing, however, parental wishes should be accommodated as far as professional judgement and conscience will permit, but no further. It is vital that that is understood by all.[81]

The significance for understanding the limits of the professional judgement of conscience in the future care of a seriously ill or dying child is threefold. First, it would enable a better understanding as to why, in cases referred to court, judges usually agree with the child's clinicians rather than parents. This is not out of deference to the medical profession or that the clinicians are better placed than parents

[77] *Montgomery v Lanarkshire Health Board* [2015] UKSC 11, [75].
[78] ibid, [81].
[79] Smith (n 20).
[80] *Re Wyatt (a child) (medical treatment: continuation of order)* [2005] EWCA Civ 1181, [86].
[81] *Re Wyatt* [2005] EWHC 2293, [40].

to decide what is in the best interests of the child 'in the widest possible sense', but because continued provision of treatment has gone beyond the limits of what is professionally conscionable. Secondly, explanation as to why the clinicians cannot agree to the treatment parents want for their child may serve to assist parents to understand that the limits of what is possible have been reached and prevent the need for court intervention. Thirdly, decisions to end life-sustaining medical interventions on a seriously ill child will always be extremely difficult, and where they follow disagreement with the responsible clinicians and the decision of a court, they will inevitably be extremely distressing. It is important to appreciate that this conclusion results from the demonstration by clinicians that they have reached the limits of the professionally possible and permissible in their professional judgement of care for the child, not a competing view of what is best.